

B.E.A.T. Cancer

Gap Analysis

May, 2014

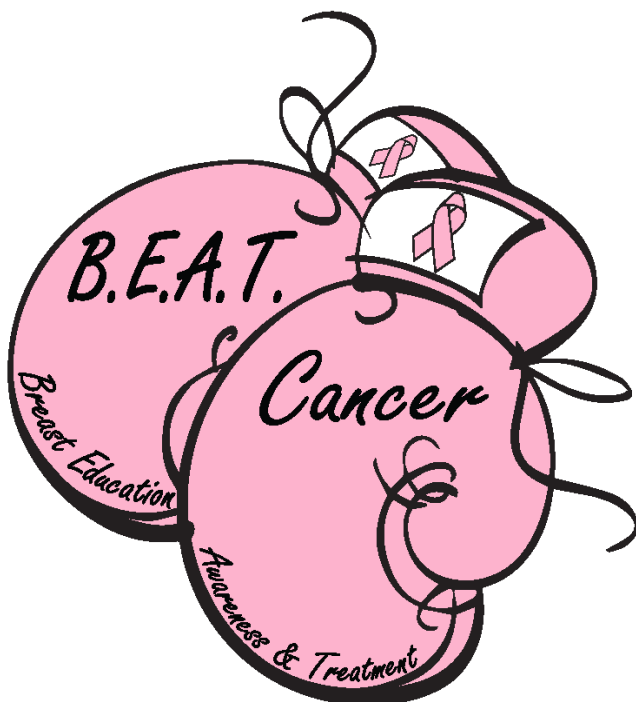


Table of Contents

Executive Summary	4
Prince William Health District Breast Cancer Statistics.....	5
Table 1 – Death Rates for Prince William Health District, all zip codes	5
Table 2 – Virginia Breast Cancer Incidence, Staging, Mortality & Screening Data by Race	5
Figure 1 - Age-adjusted and final-adjusted estimates for mammography use among white and black women, Behavioral Risk Factor Surveillance System, 1995-2006.	6
Potomac Health Foundation – Area Served.....	7
Table 3 – Breast Cancer Incidence by Year and Zip Code	7
Figure 2 – Potomac Health Foundation (PHF) Map, Areas Served.....	7
Risk Analysis – Messaging and Confusion.....	8
Methodologies	8
B.E.A.T. Cancer Coalition.....	8
Survey Tools	9
Figure 3 - Screening Survey, Question 5	10
Top Two Priorities	11
Identified Needs and Gaps.....	11
Screening / Treatment	11
Figure 4 – Screening Survey, Question 6	12
Medicare	13
National Breast & Cervical Cancer Early Detection Program (NBCCEDP): Every Woman’s Life (EWL)...	13
Women Falling Outside FPL (Federal Poverty Level Guidelines)	14
Lymphedema.....	16
Reconstructive Surgery (post-mastectomy).....	16
Socioeconomic Factors	17
Transportation	17
Childcare	17
Food and Nutrition.....	18
Body Image Products	18
Legal Help.....	19
Other / Miscellaneous Needs	19

Psychosocial Factors	20
Summary.....	21
References.....	22
Appendix A: Notes on Virginia Cancer Registry Data	23
Appendix B: Survey (Positive Reading / Diagnosis)	24
Appendix C: (Pilot) Screening Mammogram Survey.....	28

Executive Summary

Breast cancer is the second leading cause of cancer deaths in women in the United States. Despite national (and international) research efforts and highly focused and robust studies, women born in the United States have, on average, a 12% (or one in eight) lifetime risk of developing breast cancer. According to the American Cancer Society, female breast cancer incidence rates began to decrease in 2000 after increases for the two previous decades. By 2009, the incidence rate had dropped to 115.1/100,000 women from a rate of 125.7/100,000 in 2000; this decrease was attributed to the decline in use of post-menopausal hormone therapy following the publication in 2002 of the study results of the Women's Health Initiative, which showed a correlation between the use of hormone therapy and an increased risk of breast cancer and heart disease.

African American women in Virginia have a lower breast cancer incidence rate than Caucasian women (124.4/100,000 v. 126.2/100,000 includes 89.4/100,000 Latina), but their mortality rate is higher. Virginia's average yearly death rate for African American women was 38.2/100,000 compared to 28.7/100,000 Caucasian women during the same time period. Among the state's 35 health districts, the Prince William Health District (PWHD) ranks at number 29 for incidence, with a mortality rank of 26 and a mammogram screening rank of 34 (only Arlington ranks lower than the PWHD for screening). These data were obtained primarily from the Virginia Cancer Registry, which utilized several additional and secondary sources (such as BRFSS, or the Behavioral Risk Factor Surveillance System) to create this compilation. Additionally, Virginia's rank for local staging (which increases treatment options and decreases mortality) is 13, with 58% of breast cancer patients diagnosed at a local stage.

The CDC's Community Health Status Indicators Report for Prince William County shows that in 2010, women aged 50-74 years who had a mammogram in the previous two years demonstrated a 73.2% rate for African American women, and a 72.8% screening rate for Caucasian women (69.7% for Hispanic women). However, the Susan G. Komen for the Cure 2010 Community Profile Report – National Capital Area identified the need for more outreach to address specific barriers which may prevent women from seeking care. In particular, it noted that women in the Prince William Health District did not trust the screening process and did not feel that it saved lives. In addition, it found that many women worried about the cost of obtaining a screening, a concern echoed in the responses to the screening survey conducted by the B.E.A.T. Cancer (Breast Education, Awareness and Treatment) coalition.

This gap analysis attempts to address some of the causative factors for these findings and disparities, and serves as a reference tool for the B.E.A.T. Cancer coalition in its determination of the top two priorities and consequent strategies as outlined in the grant proposal submitted to and approved by the Potomac Health Foundation.

Prince William Health District Breast Cancer Statistics

Table 1 – Death Rates for Prince William Health District, all zip codes

Year(s)	Health District	All Races		White		Black	
		Deaths	Rate	Deaths	Rate	Deaths	Rate
2002-2006	Prince William (all zip codes)	186	27.9	145	28.2	31	25.5
2007-2011	Prince William (all zip codes)	199	23.5	152	24.8	39	22.4

Source: VDH, Division of Health Statistics, September 2013.

Table 2 – Virginia Breast Cancer Incidence, Staging, Mortality & Screening Data by Race

Race	Incidence ¹			Staging ²	Mortality ³			Screening ⁴	
	Count	Rate per 100,000	95% CI	Percent local stage	Count	Rate per 100,000	95% CI	Prevalence Mammography	95% CI
Black	4,881	126.1	122.5-130.0	53%	1,299	33.0	31.2-34.8	81.1%	77.1%-84.6%
White	20,824	124.2	122.5-126.0	63%	3,916	22.3	21.6-23.0	77.7%	75.8%-79.4%

Sources: Incidence and percent local staging (VA Cancer Registry); mortality (VDH Division of Health Statistics); screening prevalence (Behavioral Risk Factor Surveillance System).

¹ Based on combined 2005-2009 data. Rates are age-adjusted to the 2000 U.S. standard population.

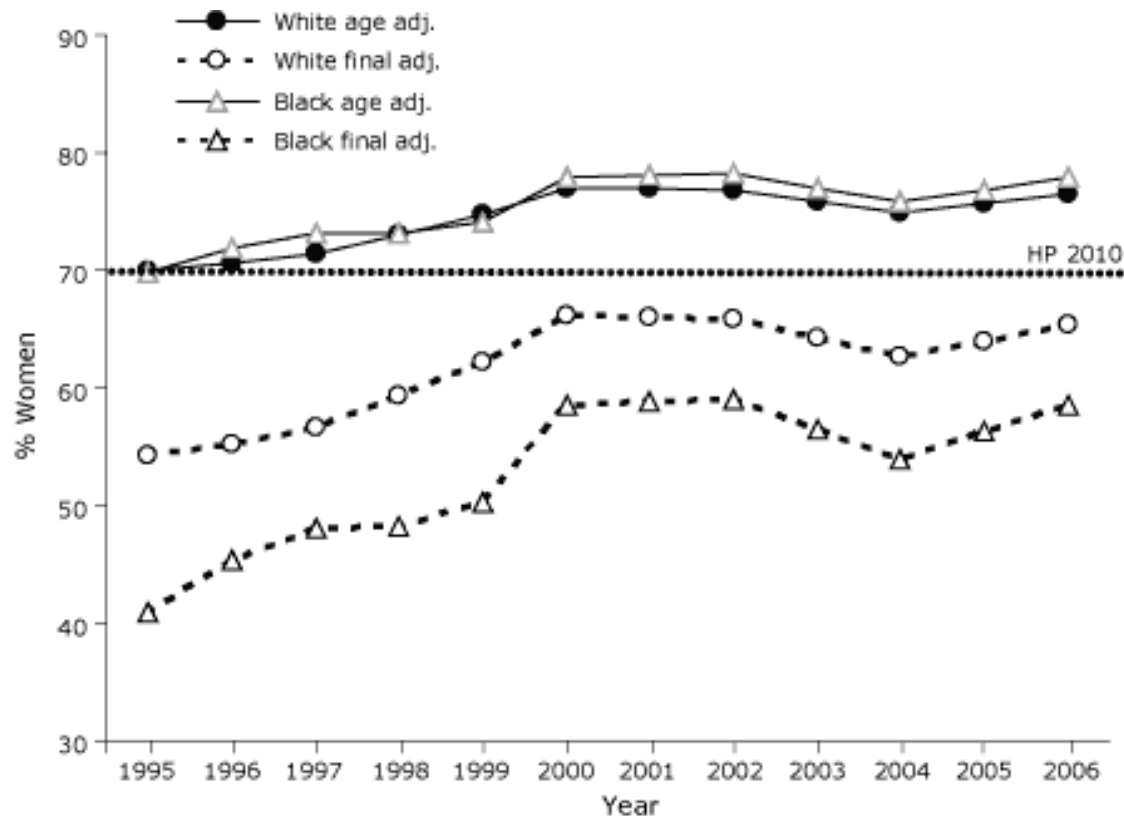
² Based on combined 2005-2009 data. Percent of Local Stage cancers reported using the Summary Staging System.

³ Based on combined 2006-2010 data. Rates are age-adjusted to the 2000 U.S. standard population.

⁴ Behavioral Risk Factor Surveillance System is a national telephone survey of adults 18+. Breast Cancer Screening = Percent of women age 40 years and older reporting having a mammogram in past two years. Based on 2008 and 2010 data (pooled). Percentages are population-weighted.

The above table reflects incidence, staging, mortality, and screening rates for the entire state of Virginia; the state does not maintain zip-code level data for its health districts.

Figure 1 - Age-adjusted and final-adjusted estimates for mammography use among white and black women, Behavioral Risk Factor Surveillance System, 1995-2006.



The screening rate for older women fell after the correlation between hormone replacement therapy and breast cancer became widely publicized.¹ According to research published in the journal *Cancer* (2011), “The change in HT use was associated with the drop in mammography use for women ages 50 to 64 years but not for women aged ≥ 65 years.” The article went on to say that “Women aged ≥ 65 years were more likely to report a recent mammogram if they also reported younger age (ages 65-74 years), more education, a usual source of care, having Medicare Part B or other supplemental Medicare insurance, excellent health, any race except non-Hispanic Asian, talking with an obstetrician/gynecologist or other physician in the past 12 months, or were currently taking HT.”

¹*Cancer, Was the drop in mammography rates in 2005 associated with the drop in hormone therapy use?*, Volume 117, Issue 24, pages 5450–5460, 15 December 2011.

Retrieved from <http://onlinelibrary.wiley.com/doi/10.1002/cncr.26218/abstract>

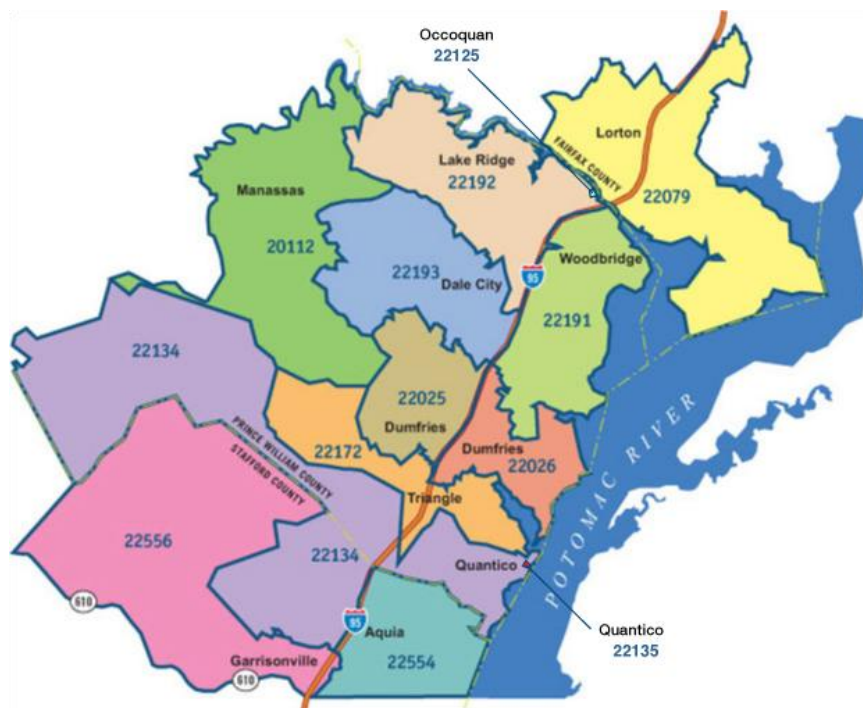
Potomac Health Foundation – Area Served

The Potomac Health Foundation serves communities in the eastern end of the Prince William Health District (see map below). Healthcare practitioners, community leaders and stakeholders from these territories were invited to join the coalition and share information and resources. Data from the Virginia Department of Health’s Cancer Registry demonstrated the following breakdown of breast cancer patients for the years 2006-2011:

Table 3 – Breast Cancer Incidence by Year and Zip Code

	2006	2007	2008	2009	2010	2011	Total for zip code
22025 Dumfries	17	21	18	13	12	8	89
22026 Dumfries	9	9	6	7	10	9	50
22134 Quantico	0	1	0	1	2	2	6
22172 Triangle	0	5	4	5	5	4	23
22191 Dale City	39	29	30	32	24	23	177
22192 Dale City	43	31	33	31	34	30	202
22193 Dale City	42	33	35	31	28	36	205
Total for year	150	129	126	120	115	112	

Figure 2 – Potomac Health Foundation (PHF) Map, Areas Served



Risk Analysis – Messaging and Confusion

Assessing any one patient's breast cancer risk can be formidable for a healthcare practitioner, but overwhelming and nearly indecipherable for many women. Not only have the messages and best practices changed over the years, but many of the guidelines used by the major organizations and institutions (American Cancer Society, National Cancer Institute, National Comprehensive Cancer Network, and the U.S. Preventive Task Force) vary widely and may create confusion and uncertainty.

The guidelines are broken down by age groups (40 to 49, 50 to 69, 70 and older); there are no guidelines for younger women other than a CBE (clinical breast exam) every 3 years (unless they fall into one of the higher risk categories, which constitute several pages of tables and data).

Methodologies

The data collection process for this gap analysis included the formation of coalition, brainstorming, identifying resources (and lack of resources), and prioritizing gaps. Two survey tools were developed and implemented (see Appendices); to date, eleven responses have been collected for the positive reading / diagnosis survey, and forty-two responses have been collected for the screening survey. Sentara Northern Virginia Medical Center has implemented the use of this survey tool in its radiology facilities (including the mammovan), and data collection will continue beyond this gap analysis.

B.E.A.T. Cancer Coalition

Monthly meetings with coalition members of the B.E.A.T. Cancer program have helped to outline several areas of concern which may present barriers to underserved / underinsured women in the eastern portion of the Prince William Health District. Representatives from local agencies and organizations including ACTS, the Va. Breast Cancer Foundation, Nueva Vida, the National Coalition of 100 Black Women and the Area Agency on Aging were involved, as well as practitioners from Sentara Northern Virginia Medical Center, the Prince William Area Free Clinic, INOVA Physical Therapy and the Greater Prince William Community Health Center. In addition, the Virginia Department of Health Northern Virginia Regional PIO (Public Information Officer), the Community Services liaison for the Town of Dumfries, the Director for Congressman Connolly's Prince William office, and the director for Breath of Hope Integrative Therapies were involved in the data gathering process and attended coalition meetings.

The brainstorming efforts during these meetings helped to identify the resources available (and lacking) in the community and the prioritization of strategies to address the gaps. The coalition determined that the top two priorities are the need for a comprehensive resource guide, which will be updated on a regular basis; and the formation of workgroups to address the following needs: 1) access to care / supportive services, 2) education / outreach, and 3) sustainability / funding.

Survey Tools

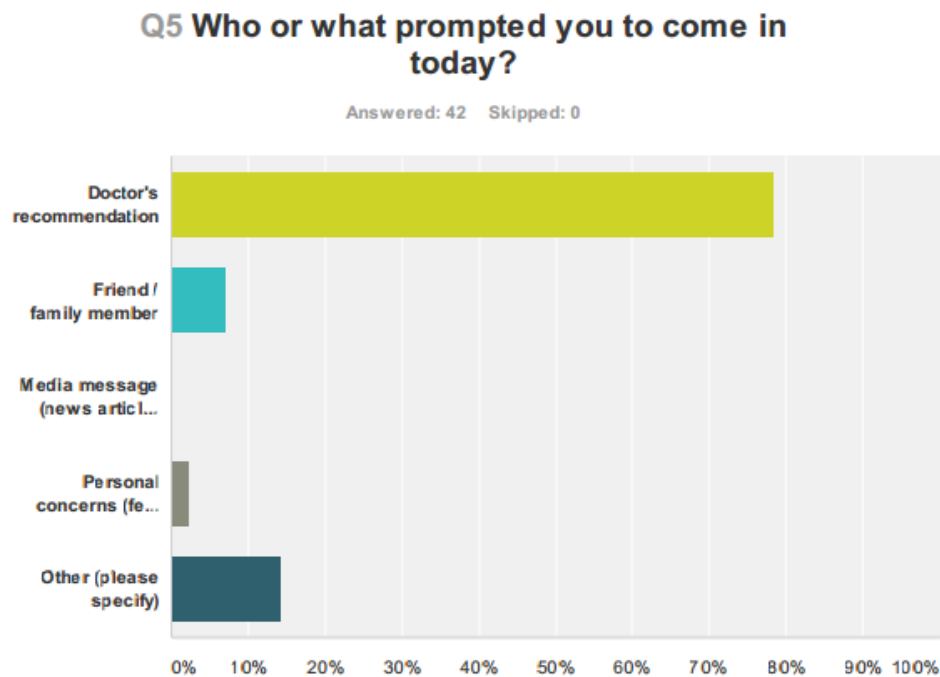
Part of the gap analysis involved the use of survey tools, one for those women who had received notice of a positive result on their mammogram report or a diagnosis of breast cancer and one for those women who were undergoing a mammogram either for the first time or as part of their annual healthcare process (see Appendices B and C).

The positive reading / diagnosis survey was made available online at www.Facebook.com/pwbeatcancer and on Survey Monkey's Website at <https://www.surveymonkey.com/s/L7WCRWX>. Additionally, coalition members were given a digital copy of the survey to print out and administer at their facilities to their breast cancer patients. The response level was not as robust as had been hoped, in part because it takes time to build an online presence and in part because timing can be a significant part of the successful administration of any survey tool. Patients receiving a new diagnosis may not be willing or in the right frame of mind to respond to a survey; physicians and practitioners may have other, more pressing concerns to attend to and put the survey on the back burner; and there may not have been sufficient numbers of newly-diagnosed breast cancer patients (or patients with a positive reading requiring follow-up) during the timeframe of the administration of the survey to obtain a more robust result.

Continued implementation and administration of the survey tool can help further flesh out these data and clarify the most important barriers and demographics of the patients. Additionally, focus groups can help to delineate in more detail some of the thoughts and beliefs behind the behaviors delineated in this study.

The screening survey demonstrated the influence of healthcare practitioners in the decision-making process for patients relative to obtaining a screening mammogram. Because younger women may seek care more frequently from ob/gyn specialists, while older women may seek most of their care from primary care practitioners, it may be necessary to develop different messages and strategies to reach different age groups.

Figure 3 - Screening Survey, Question 5



Answer Choices	Responses	
Doctor's recommendation	78.57%	33
Friend / family member	7.14%	3
Media message (news article, TV show)	0.00%	0
Personal concerns (felt a lump, noticed something different, etc.)	2.38%	1
Other (please specify)	14.29%	6
Total Respondents: 42		

As previously mentioned, women in the Prince William Health District have concerns about the cost of a mammogram screening. The education and outreach workgroup of the coalition may determine the need to further research these concerns in order to improve understanding about resources available and quantify cost barriers for mammogram screenings.

Top Two Priorities

One of the goals for the coalition was to identify the top two priorities for the B.E.A.T. Cancer program and to strategize methodologies to address these priorities. The top focus of discussion at many of the meetings was the lack of a cohesive source of centralized information for practitioners and agency and organization representatives. It was decided by the coalition that a resource guide, which would be made available online and updated regularly through the use of a “dropbox” (for healthcare and resource providers to provide current information). It is anticipated that this guide will be completed by late June, and will encompass information about community (and state and national) resources for underserved / underinsured women seeking help with financial issues, childcare, transportation, lymphedema, and support services, among other needs.

Currently, each practitioner / facility maintains its own list of resources, and the need to share and update this information quickly rose to the top of the priority list. It is anticipated that, once completed, a digital version will be sent to each coalition member and will be posted on the Facebook page, as well as on the “Community Reports” page of Prince William Health District’s website.

The second priority was identified as access to healthcare (screening / diagnosis / treatment) and supportive services. Part of the strategy to address this effort will be the continuing effort to collect data, as well as increasing outreach activities such as education, practitioner awareness initiatives, and community events designed to reach women who may be unaware of or lack access to the health district’s services.

Identified Needs and Gaps

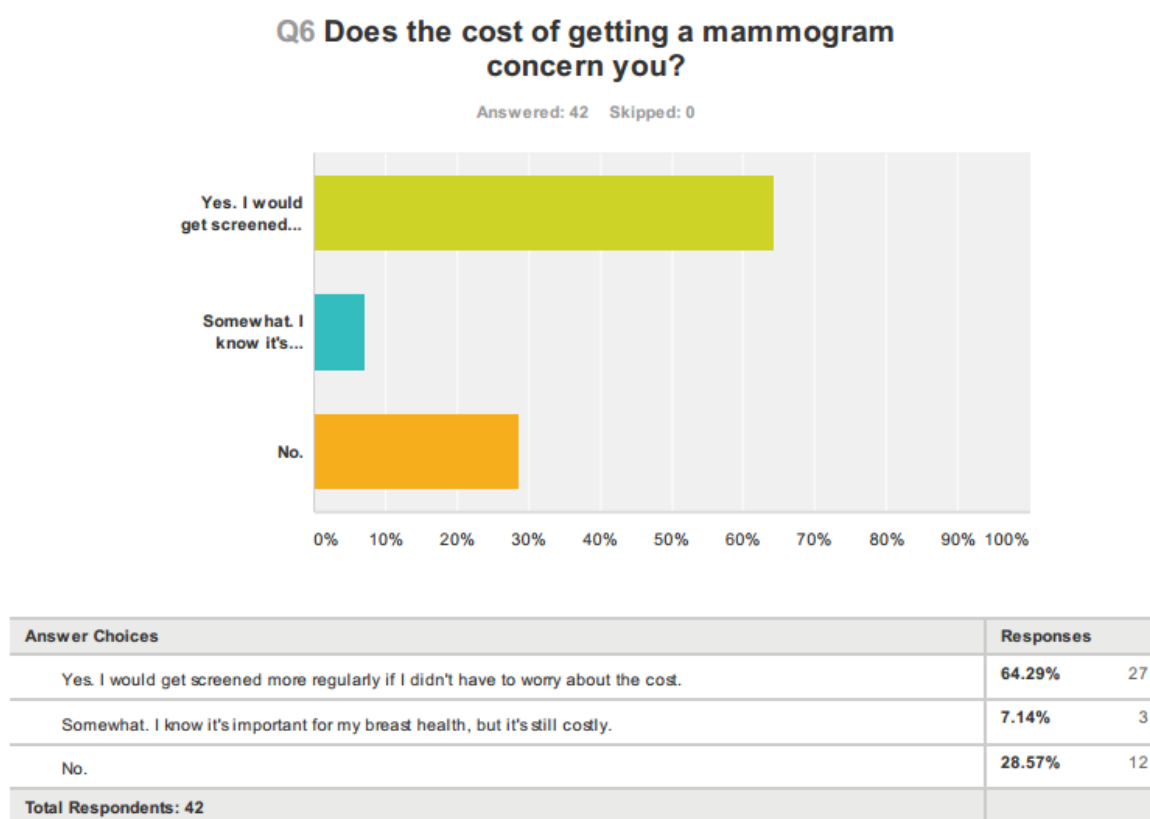
Using a gap analysis worksheet, coalition members worked to identify the recognized and perceived needs of underserved / underinsured breast cancer patients in eastern Prince William Health District. The worksheet provided the opportunity to discuss topics including screening, treatment, informational needs, psychosocial and socioeconomic factors (transportation, childcare, legal needs, food & nutrition). Resources currently available in the community were identified and discussed, as were potential sources of assistance and possible strategies to address gaps in these areas. While a comprehensive resource guide will help to provide detailed contact and program information for these resources, several areas remain challenging and subject to budget cutbacks, program changes, and stricter eligibility requirements.

Screening / Treatment

As the pilot screening survey demonstrated, there are myriad reasons why women of all ages postpone or avoid getting a mammographic screening on a regular basis. Among the most common reasons were lack of time, fear of the results, denial of importance or need, and misperception about cost. Indeed, in

the Komen Foundation's 2007 Breast Cancer Mortality Report, the paradox between true and perceived costs associated with screening and treatment created more questions than it answered. The study found that although many women recognized that there were free or reduced-cost services available, these same women named cost as among the "most significant barriers" to seeking treatment and even went so far as to link cost to the increased mortality rates for underserved / underinsured women.

Figure 4 – Screening Survey, Question 6



Yet it remains unclear how many uninsured women would avail themselves of a state screening / treatment program if it expanded its income eligibility guidelines (from 200% of the poverty level to 250% of the poverty level). Analysts have noted that this is an extremely difficult number to ascertain, and with the implementation of the Affordable Care Act, it is likely that this question will remain unanswered for some time. Coverage of mammograms for breast cancer screening is mandated by the Affordable Care Act, which provides that these be given without a co-pay or deductible in plans that started after August 1, 2012. This does not apply to health plans that were in place before the law was passed (called grandfathered plans).

Additionally, many women remain ineligible for free or reduced fee treatment services because of their citizenship / documentation status. While these women may be eligible for screening services, they may not qualify for treatment, and are often sent to state research universities (including University of

Virginia and MCV/ Virginia Commonwealth University) for follow-up, which presents barriers in terms of time and transportation (neither facility is conveniently located to the eastern Prince William Health District).

The Prince William Area Free Clinic treats a number of underserved breast cancer patients in the area, and refers as many as possible to local practitioners and facilities (including Sentara's Northern Virginia Medical Center). However, state breast and cervical cancer screening programs stemming from the Breast and Cervical Cancer Prevention and Treatment Act of 2000 may exclude many women from eligibility for Medicaid-funded treatment services if they are screened and/or diagnosed with breast cancer outside of a state program. In the PWHD, women who receive care through a PHF (Potomac Health Foundation) facility or program may still qualify for treatment and continued care, or may be eligible for charity care through less stringent qualification guidelines.

Medicare

Women 40 and older are eligible for a screening mammogram every 12 months. Medicare also covers one baseline mammogram for women between 35–39 years of age (must demonstrate higher risk, such as family history of breast or ovarian cancer, or lumps or other signs and symptoms, or presence of BRCA 1 / BRCA 2 genetic risk). There is no co-pay as long as the doctor accepts assignment (agrees to the Medicare / Medicaid payment guidelines).

Yet statistics show that approximately 50% of women eligible for Medicare coverage avail themselves of a screening mammogram. Some of the reasons for this trend were discussed earlier, and the coalition discussed methods to encourage older women to overcome the barriers preventing them from seeking screening. One barrier included access to facilities due to transportation difficulties. The Sentara mammovan, with the help of representatives from the Area Agency on Aging, might be able to help encourage women visiting the area's senior centers to update their mammograms by receiving them at the centers and encouraging and supporting each other to undertake the procedure.

National Breast & Cervical Cancer Early Detection Program (NBCCEDP): Every Woman's Life (EWL)

In the Prince William Health District, uninsured or underinsured women may get access to breast (and cervical) cancer screening and treatment under the following guidelines:

- Female between the age to 40-64 years old
- Primary residence in Virginia.
- At or below the 200% of the Federal Poverty Level.

- No health insurance or limited health insurance that does not cover breast and cervical cancer screening and treatment.
- All women must have their eligibility completed prior to enrollment and annually. They must meet income criteria in order to reenroll. Those who do not qualify should be given a Community Resource List to seek care outside the health department if they desire. They may still be eligible for health department services, but not through the EWL program.
- **Note:** The Federal Poverty Guidelines are updated annually. This update will be released by the EWL program to the providers and become effective February 1 of that year.

Two PWHD clinics handle eligible patients during monthly clinics (Woodbridge) and based on presentation and symptoms (Manassas). Patient eligibility requirements must be met at least two weeks prior to an EWL clinic appointment. Women entering EWL from an internal referral source will be facilitated entry into clinic by a staff member. Women entering EWL from external referral sources will be directed to the EWL referral line, which is monitored by public health nurses.

Women Falling Outside FPL (Federal Poverty Level Guidelines)

For some women, particularly those undergoing major life changes such as loss of job or divorce, meeting federal poverty guidelines may be difficult to achieve. These women may appear to have access to assets based on their current housing situation, previous employment, or bank and savings assets, yet the financial demands of breast cancer treatments can be formidable and many breast cancer patients find themselves falling into a “donut hole” of ineligibility.

Some resources have been identified, such as the Patient Advocacy Foundation, the CFAC (Cancer Financial Assistance Coalition), Crickett’s Answer for Cancer, and the Chronic Disease Fund. As the rules for employers requiring third party insurance coverage for their employees changes due to the Affordable Care Act and the changing economic climate, the number of these women who previously enjoyed more robust coverage – or lost it altogether – may strain the resources of these charitable organizations and create hardships for larger numbers of breast cancer patients who find themselves without the assets and resources they previously enjoyed.

In addition, most programs exclude younger women (<40) from their eligibility guidelines. Some of these women may be facing the dual burden of raising young children and dealing with their own healthcare needs. For working women in jobs without sick leave, they face the added burden of lost pay to accommodate medical visits and treatment needs.

In Virginia, women 40 years of age and older may self-refer for a mammogram; no prescription required. However, without a clinician or practitioner for a screening facility to send mammograms results to for follow-up, many of these women were turned away from obtaining a mammogram. One success story for this coalition has been the implementation of a new program on the Sentara mammovan. When such a patient (lacking a primary care provider or practitioner) requests a screening, a list of physicians is

consulted and the results are faxed to one of these healthcare providers based on the patient's preference (when possible), availability and schedule of the physician, and the acquisition of good contact information from the patient. This would not have been possible before the development of this coalition and its recognition of this gap in screening access.

Women seeking screening services on Sentara's mammovan must be pre-screened for determination of financial responsibility and/or eligibility for sliding scale / reduced fees. The Greater Prince William Community Health Center, the Prince William Area Agency on Aging, the Prince William Area Free Clinic and the Prince William Health District have partnered with Sentara and its mammovan to help provide screening and continuation of care services for women residing in the areas served by the Potomac Health Foundation.

Lymphedema

In the Prince William Health District, there are only two facilities available to treat lymphedema patients: Inova Physical Therapy (Woodbridge), and Novant Prince William Therapy (Manassas). Because massage therapy for lymphedema is a specialized skill requiring separate certification, finding qualified therapists can be a challenge, particularly for patients who lack insurance.

While organizations such as LymphedDivas and Cricketts offer resources to help provide garments for patients lacking coverage, their assets and resources are limited and the need for these compression garments is lifelong. In addition, many patients lack the support system and day-to-day help required to properly wrap the garments, especially for lower limbs. This can greatly reduce compliance rates and exacerbate the healthcare problems for these lymphedema patients.

Several national organizations and associations may be able to offer additional help for the purchase of the garments, but professional measurements are required. In addition, without proper massage therapy and/or supportive help at home, patients may find themselves struggling to apply the garments. Identifying qualified community volunteers can be a key component in the reduction of this gap, and finding ways to encourage qualified massage therapists to volunteer time (or to certify other massage therapists) is a goal often discussed by the coalition.

Reconstructive Surgery (post-mastectomy)

Accredited centers must at least mention post-mastectomy reconstructive surgery options, but funding can be formidable for the uninsured. Sentara Northern Virginia Medical Center has a grant-funded program available to pay for the OR, but plastic surgeons are worried about the compensation piece for their services. Both MCV and UVA have reconstruction programs for the uninsured (undocumented patients would not qualify). There is a need to identify providers who would be willing to do reconstructive surgery on a reduced or sliding scale. Sentara does maintain a program which provides the surgeons with some reimbursement for their services. State institutions are required to take patients, so private facilities refer patients to these state institutions regardless of distance.

Socioeconomic Factors

Preliminary data from the surveys and from informal interviews (as well as several studies) suggest that the lack of community knowledge about breast care resources is a problem for both patients and healthcare practitioners. Patients often depend upon their clinicians and/or patient navigators to help guide them toward resources and sources of help and support. Included among the most often discussed and recognized needs are health-related transportation; childcare; food and nutrition; body image products; and legal help.

Transportation

Perhaps one of the most challenging barriers for women seeking breast healthcare is the lack of transportation for health-related visits. While programs do exist, their limitations can be restrictive. The PRTC (Potomac and Rappahannock Transportation Commission) implemented a grant-funded program called Wheels to Wellness, which provides a “budget card” for patients to pay for cab rides to medical appointments and pharmacies. To qualify, a patient must be over 80; disabled; or fall under specific poverty guidelines. However, the program has enjoyed community support and success, and has been invited to apply for continued funding through the next grant cycle.

The American Cancer Society (ACS) maintains a list of volunteer drivers under a program called “Road to Recovery.” While this list may be robust in some areas, it is unclear how strong the program’s volunteer pool is at any given time in the Prince William Health District. The ACS has recently undergone budget cuts, which has created further challenges for the organization to find and organize volunteers. In addition, requests must be made four days in advance of the appointment, and the drivers are often unwilling to wait for the patient to finish treatment and/or complete their appointment, leaving the patient stranded at the medical office or facility.

Similarly, Medicare’s NEMT (non-emergency medical transportation) program has found itself straining to meet all but the most urgent needs, and is often not the first or even second contact for transportation needs. A subcommittee has been formed to identify alternative community resources, including assets compiled by Volunteer Prince William, an affiliate member of the Points of Light Institute & Hands On Network charged with promoting “volunteer management best practices through training and consulting services.”

Childcare

As mentioned previously, many breast cancer patients may find themselves unable to make or meet appointments because of childcare needs. While the transportation programs mentioned above will accommodate children, it can be difficult (or impossible) for the patient to receive treatment while supervising young children.

Facilities such as hospitals, outpatient clinics, and physicians' offices are often ill-equipped to meet these childcare needs, especially for the very young. They may offer a small play area or lobby, but supervision services are often not available and liability concerns must be taken into account.

Licensed childcare agencies (such as Minnieland / SAC – School After Care) and private home facilities may offer resources for breast cancer patients. In addition, faith-based organizations sometimes offer “Mommy & Me” programs or childcare services for their congregants. The office of Congressman Gerald Connolly maintains a database of resources for its constituents, and a list of licensed home healthcare providers has been obtained. One suggestion was to ask older Girl Scouts looking to achieve a Silver or Gold award to call these home healthcare agencies and compile a database of providers willing to offer free or reduced-fee services for the children of breast cancer patients. Culling (and updating) this list will require the help of a pool of volunteers, and concerns of liability and special needs must always be taken into account.

Food and Nutrition

The local food pantry administered by ACTS offers donations of foodstuffs through donations from local grocers and farmers' markets. However, this pantry is open to all eligible residents of Prince William County, not just breast cancer patients. The Food and Friends organization offers nutritional counseling, groceries-to-go, and home delivered meals for patients with chronic illnesses.

In addition, the Area Agency on Aging's Meals on Wheels program (for senior citizens) may be able to provide home delivered meals for eligible senior patients, although this program may not be able to meet certain dietary needs and restrictions for the chronically ill.

Body Image Products

The American Cancer Society's “Look Good, Feel Better” program offers help with beauty tips and applying makeup for cancer patients. For children, a program called Locks of Love provides wigs and pieces to help kids deal with the potentially devastating effects of the loss of hair due to chemotherapy and radiation.

Often, new resources develop (and close) based on personal experiences with breast cancer. One such resource, “I'm Still Me,” served the PWHHD area for years, offering wigs, swimsuits, prostheses, scarves, and other products for breast cancer patients. The owner and founder had to close its doors because of a recurrence of the disease, and while other national resources may be available, the personal touch from a local source can make all the difference for women facing changes to their appearance.

Many salons sponsor fundraising events to help offset the costs of wigs for underserved patients, but as these resources are not constant, it is imperative for the community to maintain a source of updated

information to keep current about funding and products available for these breast cancer patients. Some patients have expressed great concerns about their appearance following radiation, surgery, or chemotherapy treatments, so providing access to products is sometimes not enough. These women need to also feel good about their appearance and get encouragement and support from their peers.

Legal Help

Women facing breast cancer often have work-related concerns based on the demands of treating breast cancer. They want (and need) to know their rights and often do not have the resources to get proper legal advice. They may be undocumented workers without access to HR representatives, or they may lack an understanding of how and what paperwork to file to collect disability or even keep their jobs.

Additionally, single parents may face concerns about custodial issues (i.e., “If I’m too sick to care for my kids, who will take them? Will I lose them?”) Finding professional help and getting accurate information can be crucial for their decision-making processes when they are faced with breast cancer.

There are organizations set up to handle these concerns specific to cancer patients. One is the Lance Armstrong Foundation; the other is LINC (Legal Information Network for Cancer). Because many practitioners focus on the treatment needs of the patient, and family members and support organizations lack this specialized legal knowledge, it is important that patients be made aware of their rights through the free (and reduced) services of these resources.

Other / Miscellaneous Needs

Breast cancer patients often find themselves drained of energy, support, and finances, and often struggle to take care of things like housekeeping or pet care. They may be distressed to be unable to perform basic household chores, or have difficulties finding someone to care for their pets, often having to resort to shelters because they find themselves unable to care for their animals.

Organizations offering short-term fostering, including some kennels, have begun to address this gap and can sometimes find volunteers willing to make “house calls” to care for the animals.

And an organization called “Cleaning for a Reason,” a nonprofit serving the entire United States and Canada, has partnered with maid services to offer professional house cleanings to help women undergoing treatment for any type of cancer. Patients wishing to avail themselves of this service must provide a physician’s note confirming they are receiving treatment. They will then be matched with a maid service, who typically takes on two patients at a time, each of whom receives one general house cleaning per month for four consecutive months.

Psychosocial Factors

Many women, as mentioned previously, delay getting a mammogram or treatment because of fear, denial, or mistrust of the medical system. The B.E.A.T. Cancer positive reading / diagnosis survey tool found that while many women based their decisions on the advice and guidance of their physicians, many others relied heavily on family, friends, and faith-based organizations to help make decisions about their healthcare.

In addition, undocumented women may face fears not only about costs associated with treatment but also about their citizenship status. One organization, Nueva Vida, has developed an outreach program to offer support and information for breast cancer patients in the Prince William Health District. Additionally, there are many online support systems available, and patients may even set up a free website for family members and friends to offer encouragement and get updates about the patient's condition.

Overcoming mistrust of the medical system can be a more formidable challenge. Several studies have shown that outreach programs designed and executed through the efforts of local beauty salons have enjoyed great efficacy in overcoming these misgivings, because the salon owner/operators offer peer-based guidance (through training programs), which often helps to create a sense of trust and openness.

For children facing the illness of a parent, the “what-ifs” can be overwhelming. They often do not understand why mommy can't play or take care of them, and become fearful and anxious. One organization, called Kidscope, has addressed this need by offering information and products to help children understand what is happening in their families.

Finding local therapists willing and able to meet the needs of the families and patients facing breast cancer is an ongoing challenge for the coalition.

Summary

This gap analysis, while still a work in process, has attempted to address the myriad and complex factors affecting the underserved / underinsured women of the Prince William Health District. These factors include access to healthcare, psychosocial factors (fear, denial, mistrust) and socioeconomic factors (transportation, childcare, food and nutrition).

Because breast cancer will affect one in eight women during their lifetime (and is the second leading cause of cancer death), the importance of understanding the barriers these women face cannot be overstated. Breast cancer has a five-year relative survival rate of 98.0 percent if diagnosed in its earliest (local) stage, when it is most curable.¹ However, those patients most vulnerable to delay in diagnosis and treatment face far grimmer statistics, in part because the tumor may be at a more advanced stage or of a more aggressive nature. This is particularly true for younger women, who may not be aware of their risk and may lack adequate resources.

Despite self-reported screening rates approaching 78% for women of Virginia 40 years and older, this number drops significantly for less educated, lower income (and uninsured) women. Increasing screening rates, then, particularly for older women, is an important goal for this coalition. Additionally, the creation of a comprehensive (and regularly updated) resource guide, for both patients and practitioners, is of primary importance and will require the input of the coalition and of other community agencies and organizations.

Continuing the collection of data, through survey tools and focus groups, will help to further pinpoint areas requiring more focus and effort. The B.E.A.T. Cancer coalition's goals for the future must include careful analysis of this data and redoubled efforts to identify available resources to address the gaps and barriers identified in this analysis.

Decreasing the time from diagnosis to treatment is an important effort in the reduction of mortality rates related to breast cancer. Outreach efforts must include not only educational components but also support and networking – identifying the community's leaders and 'gatekeepers' who can reach the women most sorely in need.

¹ American Cancer Society, Cancer Facts & Figures, 2013.

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Appendix A: Notes on Virginia Cancer Registry Data

Notes on Virginia Cancer Registry Data

Data in the Virginia Cancer Registry (VCR) reflect a conservative account of the disease in Virginia. Not all hospitals, outpatient facilities, and private pathology laboratories have begun reporting cases to the registry. Further, Virginia residents sometimes travel out-of-state for diagnosis and treatment and may not be reported to the VCR. While the registry does maintain exchange agreements with cancer registries in neighboring states, there is some lag time in posting those cases. Cancer data for areas primarily in Southwest Virginia may be under-reported; interpret these data carefully. Because the completeness of reporting varies in different areas of the state, some observed differences in case counts or rates may be reporting artifacts. For instance, rates may be higher in more urbanized areas because case ascertainment may be more complete. Similarly, case reporting may be more complete for certain racial groups, cancer sites, or diagnosis stages. Cancer registry staff is not able to assess the extent to which these biases exist, so use the data with caution. Our goal is to provide valid and reliable data with which to understand cancer in Virginia and to make informed personal and policy decisions.

Virginia Cancer Registry
109 Governor Street, 10th Floor
Richmond, VA 23219

Phone: (804) 864-7866

Fax: (804) 864-7880

Internet address: <http://www.vahealth.org/cdpc/cancerregistry/>

Appendix B: Survey (Positive Reading / Diagnosis)

B.E.A.T. Cancer

Breast Education, Awareness & Treatment



This B.E.A.T. Cancer coalition with the support of the Potomac Health Foundation is distributing this survey, which is designed to help collect information about breast cancer patients in the Prince William community. The information collected will help us determine the need for additional education, screening and treatment services. This information will not identify who filled out the survey, and will only be used to help provide needed breast health services in our community.

Date: _____

1. Zip code of residence: _____
2. Community name (e.g., Cherry Hill, Town of Dumfries, Dale City): _____
3. With which racial and/or ethnic groups do you most identify?

_____ Asian	_____ Hispanic
_____ American Indian	_____ White
_____ Black	_____ Other _____
4. What type of healthcare coverage do you have (check all that apply)?

_____ Private / commercial (Aetna, Cigna, Blue Cross/Blue Shield, etc.)
_____ Medicare
_____ Medicaid
_____ TRICARE
_____ No insurance
5. At what age were you diagnosed with breast cancer? _____
6. At what stage were you diagnosed with breast cancer?

_____ Noninvasive / DCIS (Ductal Carcinoma In Situ)
_____ Local Invasive (breast only)
_____ Regional Invasive (breast and lymph nodes)
_____ Distant / Metastatic (breast and other organs)
_____ Unknown

7. Prior to your diagnosis, did you know anyone who was diagnosed with breast cancer? (Select all who apply.)

<input type="checkbox"/> Mother	<input type="checkbox"/> Grandmother (on mother's side)
<input type="checkbox"/> Sister	<input type="checkbox"/> Grandmother (on father's side)
<input type="checkbox"/> Daughter	<input type="checkbox"/> Other (please specify) _____
<input type="checkbox"/> Aunt (on mother's side)	<input type="checkbox"/> None
<input type="checkbox"/> Aunt (on father's side)	

8. Prior to your diagnosis, did you feel that you might be at risk for breast cancer?

☐ Definitely
☐ Somewhat
☐ A little
☐ No
☐ Not sure

9. What was your treatment type? (Select all that apply.)

☐ Radiation
☐ Chemotherapy
☐ Surgery (Mastectomy, lumpectomy)
☐ Alternative medicine (herbal/organic remedies)
☐ Faith / prayer
☐ Other (please specify) _____

10. Where did you receive your treatment(s)?

☐ Within the Greater Prince William area (PW County, cities of Manassas or Manassas Park)
☐ Outside the Greater Prince William area

11. If you answered "outside of the Greater Prince William area" above, why? (Select all that apply.)

☐ I wanted to receive treatment closer to work
☐ Treatment services were not available in PW County
☐ Facility/physician was recommended to me
☐ Cost & fees were lower
☐ Personal preference
☐ Other (please specify) _____

12. Rate the following influences on their impact to the decisions you made concerning your healthcare. “Weak” means there was little or no influence, and “Strong” means there was powerful influence on your decisions. For example, if you decided to do (or not do) something due to persuasion from a family member, you would put a check mark under “strong” for that item.

	Weak	Somewhat	Strong
Physician / healthcare practitioner	_____	_____	_____
Family members	_____	_____	_____
Co-workers / colleagues	_____	_____	_____
Internet resources	_____	_____	_____
Clergy / church members	_____	_____	_____
Friends	_____	_____	_____

13. Rate the following factors on the degree of difficulties you faced overcoming obstacles during and after your healthcare. “Not much” means you didn’t have a lot of difficulty dealing with the obstacle, and “A lot” means you had challenges trying to deal with the problem.

	Not much	Somewhat	A lot
Transportation	_____	_____	_____
Making appointments	_____	_____	_____
Getting good information	_____	_____	_____
Costs / financial issues	_____	_____	_____
Language/ cultural barriers	_____	_____	_____

14. How strong were your concerns about changes to your appearance and body (due to chemotherapy, surgery, or other treatments)?

- _____ Not too worried
 _____ I was concerned, but I felt like I got good information and preparation
 _____ I was concerned, and I could not get good information
 _____ I was very frightened but it wasn’t as bad as I had feared
 _____ I was very frightened and still feel that I was unprepared.

15. How strong were your concerns about side effects of treatments?

- ☐ Not too worried
- ☐ I was concerned, but I felt like I got good information and preparation
- ☐ I was concerned, and I could not get good information
- ☐ I was very frightened but it wasn't as bad as I had feared
- ☐ I was very frightened and still feel that I was unprepared.

Thank you for your time! We appreciate your feedback and will use it to help improve breast cancer healthcare in the Prince William community.

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Appendix C: (Pilot) Screening Mammogram Survey

B.E.A.T. Cancer
Breast Education, Awareness & Treatment
Screening Survey



Date: _____

1. What is your zip code of residence? _____
2. With which racial and/or ethnic groups do you most identify?
____ Asian
____ American Indian
____ Black
____ Hispanic
____ White
____ Other _____
3. Have you ever had a mammogram before?
____ Yes
____ No
4. If so, how long has it been since your last screening?
____ One year
____ Two years
____ More than 2 years ago
5. Who or what prompted you to come in today?
____ Doctor's recommendation
____ Friend / family member
____ Media message (news article, TV show)
____ Personal concerns (felt a lump, noticed something different, etc.)
____ Other _____
6. Does the cost of getting a mammogram concern you?
____ Yes. I would get screened more regularly if I didn't have to worry about the cost.
____ Somewhat. I know it's important for my breast health, but it's still costly.
____ No.
7. How did your concerns about possible pain or discomfort from the procedure affect your decision to come in today?

- ☐ Not at all. I have had them in the past and knew what to expect.
- ☐ Not at all. I have never had one but I am not worried about pain.
- ☐ A little. I knew what to expect but I still wish it was a little less uncomfortable.
- ☐ A little. I wasn't sure what to expect but I have heard things from other people.
- ☐ Quite a bit. I've had mammograms before, and it was a very unpleasant experience.
- ☐ Quite a bit. I never had one before, but I heard that it's very painful.

8. What do you believe is your risk of getting breast cancer?

- ☐ High risk
- ☐ Somewhat high risk
- ☐ Average risk
- ☐ Low risk

9. Would getting screened along with a friend or loved one make the procedure easier for you?

- ☐ Yes
- ☐ Maybe
- ☐ No

10. Do you feel that there are confusing or conflicting messages about the need for mammograms from newspapers, TV, and other sources of information?

- ☐ Yes
- ☐ No
- ☐ Sometimes

11. Which of the following factors or statements affect your decision to get a mammogram, or postpone (or avoid) getting screened? Check all that apply.

- ☐ My doctor didn't tell me I needed one.
- ☐ I don't have enough time / too busy.
- ☐ I don't have transportation.
- ☐ It's too expensive.
- ☐ I don't have anyone to take care of my children.
- ☐ I can't afford to miss work.
- ☐ Mammograms can be dangerous or can even cause cancer.
- ☐ I don't need to be screened because nobody in my family has breast cancer.
- ☐ Mammograms can lead to unnecessary surgery.
- ☐ I am too young / too old to worry about breast cancer.